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Title: Choosing health, choosing treatment: patient choice after diagnosis of localised prostate cancer

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Introduction

Patient choice is nothing new (1) but it is a motif that is increasingly mobilised by politicians, policy-makers, and health service providers across much of the Western world. Despite its global resonance, we want to make the case for considering the complexity of the contexts in which patient choice is offered. In this paper, we consider research in relation to the domain of localised prostate cancer in the UK, specifically to choosing treatment after first diagnosis. Before making some recommendations for research, the UK context is elaborated through a consideration of health policy, which is then related to changes in a specific service (the Yorkshire Cancer Centre) and research on patients' experiences of treatment.

Policy

The UK White paper entitled, *Choosing Health: making health choices easier*, outlines a commitment to patient choice. More specifically, this is a move away from a system that knows how to make people healthy to a health service that supports people in making choices about their health. Patient treatment decisions are more complicated than in other areas of a consumer society. Consumer choice in health is problematised through the often complex nature of treatment and the limited access patients have to relevant information. 'Patient choice' is evident in 2008 UK NICE (National Institute of Health & Clinical Excellence) guidelines for the diagnosis and treatment for prostate cancer where they recommend that healthcare professionals should discuss all treatment options including the adverse effects of treatments.

Implementing patient choice in the domain localised prostate cancer is not going to be without difficulties. For example, medical expertise underlies the development of trust in patient-physician communication for men with cancer (2), which may mean that patients will still expect health professionals to use their medical expertise to decide upon the best course of action. Furthermore,

there is evidence that physicians view informed patients with suspicion alienating those, for example, that use the internet to research their condition (3). Nevertheless, informing patients does affect their treatment choice (4) and even if findings that informed patients appear to be more active in their treatment and have reduced levels of psychological distress (5) lack consistency (6) informing patients does show positive effects on communication processes during periods of treatment decision making.

Unfortunately, informed patients with localised prostate cancer tend to be limited to those that are enthused and literate enough to research their condition (7). Although some do argue that providing information is an integral part of clinical practice and therefore should not be left solely to the patient (8).

Service Delivery

UK health services are implementing changes with the intention of supporting men diagnosed with localised prostate cancer in making the decision that best suits their needs and preferences. The centralisation of some specialist services, such as surgery for localised prostate cancer, will add another element to treatment choice for some men and their carers. We shall introduce one service that is implementing choice along side centralisation of specialist services to establish how UK health policy is being implemented.

Serving a population of 2.6 million, the Yorkshire Cancer Centre (YCC) is one of the largest oncology services outside London. In one of the hospitals in the YCC (St. James Hospital, Leeds) major surgical and radiotherapy services are provided for patients from Leeds, York and Harrogate. Consultations are held in a hospital local to the patient. To support patient choice after diagnostic results suggest the presence of a localised prostate cancer, the consultant will initially discuss treatment options with the patient and, where appropriate, the patient's significant other accompanying them at the appointment. The consultation is then

followed by an appointment with a clinical nurse specialist where there is greater opportunity to describe and discuss the different treatment options and their associated side-effects.

The intention of the NICE guidelines is that men with prostate cancer decide what treatment they get based on information about the choices they could make and that the healthcare service, such as YCC, is to support them in this process rather than deciding which treatment is most appropriate. As physicians are more likely to recommend the treatment options related to their specialism (9), the addition of an appointment with a clinical nurse specialist should help to minimise this bias and leave patients better informed.

Patients' Perspective

There are a number of treatment options for prostate cancer such as prostatectomy, brachytherapy, conformal radiotherapy, cryotherapy, and high-intensity ultrasound (see Box 1). Treatment can even be avoided for ever, or long delayed, as in watchful waiting or active surveillance. For those diagnosed with localised prostate cancer treatment can have significant side effects (10), which means that patient choice policies and service changes implementing those policies need to incorporate patients' experiences.

Treatment may impact on a patient's sense of identity, particularly their masculine identity, and overall wellbeing (11;12). Side effects are particularly important for those with a low or medium risk diagnosis because there is a possibility that their cancer will not be fatal, which could make it more difficult to decide if treatment is justifiable. At present there is little evidence to support a survival advantage of any particular treatment which would help make patient choice clearer (13) and we await the results of a large randomised controlled trial (ProtecT) (14). Indeed, the UK National Institute for Health and Clinical Excellence (NICE) have

issued guidance on treatment for localised prostate cancer (15) that emphasises the options available.

There is no doubt that some men will prefer maintaining their identity and quality of life to potentially securing longer-term survival through treatment with radiotherapy or surgery (16;17). In addition, these experiences of treatment are highly differentiated (e.g., 18) and even if there are distinct patterns of change in quality of life after treatment (19) there is no clear way to predict preferences for treatment. Consequently, it is little surprise that some argue that attempts to reduce mortality (e.g., 20), should be supplemented by developing a better understanding of the lived experience of dealing with the impact of prostate cancer and the decisions involved (21).

Importantly, this means supplementing a focus on the psychological processes of making treatment decisions (i.e. research on ‘decision making’) for an emphasis on the experience of periods when decisions about treatment are required. Patients place a high priority on the day-to-day practicalities of living with cancer (22) and this would seem to include the practical process of making decisions about treatment for localised prostate cancer. There is good reason for distinguishing between ‘choosing-treatment’ and ‘treatment’ periods in the prostate cancer journey because, for example, there is evidence that once a treatment decision has been made information gathering ends (2) and new behaviours are taken up in addition to treatment, such as improvements in diet (23). Service changes at YCC could help to ensure that all patients are better informed but because choosing treatment is so complicated it is important to follow up such service changes with an exploration of patients and carers lived experience of them.

Research

As it is patients and carers who actually go through the period of

deciding on treatment, they have expertise that will benefit research about patient choice not just through an advisory capacity but in the process of the investigation. More specifically, exploring patients 'experiences' requires researchers to make some assumptions when deciding which issues to emphasise and how best to explore them. There is evidence of a mismatch between the cancer research priorities of researchers

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and patients (22), which suggests that researchers may not be best placed to make assumptions about patients' experiences.

Furthermore, the first two UK National Cancer Patient Surveys (1999-2000 and 2004) found that men with prostate cancer had the worst experience of services but research was unable to offer a convincing explanation (24), which highlights the importance of moving beyond studies that use patients and carers in an advisory capacity to investigations where their expertise can benefit the process of research.

While there are attempts to consult patients about their views researchers will not be able to resolve this mismatch without drawing upon the knowledge and experience of those using cancer services (see e.g., 25). Indeed, there is a wealth of activity attempting to include patients in the design of research that is about patients and their needs (see e.g. www.involve.org.uk), which is in line with the philosophy of the discerning consumer in UK health policy. Consequently, when attempting to understand the experience of making prostate cancer treatment decisions patients and carers will be invaluable in directing, designing and running such research.

Summary Box: □ Policy: Government guidelines (from the National Institute for Health and Clinical Excellence; NICE) now recommend a number of treatment options (watchful waiting,

active surveillance, prostatectomy, brachytherapy, and conformal radiotherapy) as appropriate for each level of localised prostate cancer (low, intermediate and high risk) and says that it is patients who must decide between them.

Service delivery: UK health services are implementing changes with the intention of supporting men diagnosed with localised prostate cancer in making the decision that best suits their needs and preferences. Offering some services, such as surgery for localised prostate cancer, at large specialist hospitals (what is termed 'centralisation') will add another potentially complicating aspect to treatment choice for some men and their carers.

Patient: Treatment choice can be particularly difficult in localised prostate cancer because of the uncertainty involved. This means that it is important to follow up the policy and service changes with an exploration of patients and carers experiences of them.

Research: When attempting to understand the experience of making prostate cancer treatment decisions patients and carers will be invaluable in directing, designing and running such research

Linked Information □ Involve: www.involve.org.uk □ NICE Guideline on the diagnosis and treatment of prostate cancer:

- Quick Reference Guide:

<http://www.nice.org.uk/nicemedia/pdf/CG58QuickRefGuide.pdf> □ - Full Guideline:

<http://www.nice.org.uk/nicemedia/pdf/CG58FullGuideline.pdf>

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Box 1: Treatment Options for Prostate Cancer

	Low risk	Intermediate risk	High risk
Watchful waiting	□	□	□
Active surveillance	¥	□	x
Prostatectomy	□	¥	¥□
Brachytherapy	□	□	X
Conformal radiotherapy [†]	□	¥	¥□
Cryotherapy	x [‡]	x [‡]	x [‡]
High intensity focused ultrasound	x [‡]	x [‡]	x [‡]

Key

- Treatment option
- ¥ Preferred treatment
- x Not Recommended

- * Offer if there is a realistic prospect of long-term disease control
- † Conformal radiotherapy should be given at a minimum dose of 74 Gy (at a maximum of 2 Gy per fraction
- ‡ Unless as part of a clinical trial comparing use with established interventions

Source: National Institute for Health & Clinical Excellence. Prostate Cancer: Diagnosis and Treatment. NICE Clinical Guideline 2008: 58: 7

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